

Poster Presentation

Palliative Care 2019 Clinical Trials 2019









Joint Event on 2nd International Conference on

Palliative Care

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Clinical Trials and Pharmacovigilance



Palliative Care & Clinical Trials and Pharmacovigilance

September 23-24, 2019 | Prague, Czech Republic

Towards independent living of Alzheimer's patients in Saudi Arabia: Patterns of daily living and features of smart homes

Riyad A Alshaqi

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In recent years, elderly patients Who suffers from Alzheimer's disease face challenges to live alone safely in their own homes. Their personal care worries their relatives in case being alone in their homes. Also, the cost for care in nursing homes or hospitals is high and increases if care is mobilized to their own homes, while being not favoured in Saudi Arabian culture. This makes it necessary to create smart houses for patients to support them live an independent life in their own homes with their behaviour being constantly monitored and assisted by an intelligent artificial system to provide assessment and necessary assistance when needed, while being linked to relatives or care providers. For this reason, this poster aims to: a) Identify from previous studies common activities performed by Alzheimer's patients to define patterns of daily living in the context of Saudi Arabian. b) The overall project system structure and design. C) Identify types of personal and environmental sensors and use for independent living and Provide a generic framework implement intelligent homes for Alzheimer's patient.

Speaker Biography

Riyad A Alshaqi works in Prince Sultan Military Medical City at Saudi Arabia. His research interest is in the study of Alzheimer.

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Challenges and barriers of adequative pain management – Georgian experience

Rukhadze T

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Goal of the study – Improve quality of life of patients with cancer pain in Georgia through evaluation of needs, availability and accessibility of opioids. Questionnaire survey, analysis of patients, medical professionals, patients medical records and patients care givers were applied in the study. The several problems associated with caregivers and difficulties with respect to clinical groups, certain problems while opioids prescription, dose selection, availability of opioids, tablet forms of opioids were assessed and included in data base along with medical problems.

The 159 questioners were analysed: 84 (52.8%) patients, 53 (33.3%) caregivers and 22 (13.8%) medical professionals. In accordance with the obtained material comparative analysis was performed and study results reliability was evaluated based thereof, wherein p value indicator was considered to be statistically reliable. It is significant, that concept of Clinical Group in the practice of clinical oncology represents the unit of dispenserisation remaining from the soviet healthcare system.

Conclusions:

• Application of clinical groups in medical practice is provisional; it represents the part of post-soviet system and the unit of oncology patients' health examination. Clinical group creates a barrier in providing complete service to patients, makes it impossible to prescribe opioids to patients with medical means during anti-cancer radical treatment in case of strong pains;

• Clinical group fails to provide complete information on general condition of patient, quality of life. It is nor applied in accordance with international clinical guidelines and is maintained only in the countries of post-soviet region;

 The main barriers of non-adequate pain control and challenges in opioids availability in Georgia are: lack of the opioids, limited knowledge of medical professionals, opioid phobia between medical professionals, patients and whole population, incompliance of normative bases, legislation and regulations.

Speaker Biography

Rukhadze T is a Medical Oncologist and Professor at Tbilisi State University. Also, she serves as International Expert of Palliative Medicine and completed her Postgraduate Fellowship in Clinical Oncology at Karolisnka Hospital, Stockholm, Sweden and PhD at the age of 30 years from TSMU, Georgia. She has completed international Fellowship program at the Institute of Palliative Medicine, San Diego University, San Diego, USA. She has over 50 publications that have been cited over 37 times and her publication H-index is 3,5 and has been serving as an editorial board member of EPMA Journal.

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Video Presentation

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Self-care in palliative medicine: The pathways model

Donald Moss

Saybrook University, Canada

The major challenge for human health in the 21st century is chronic diseases and chronic conditions. This is a global problem, burdening health care systems and economies worldwide. Factors contributing to the increase in chronic illness worldwide are aging populations, rapid urbanization, and the globalization of unhealthy lifestyles.

Palliative medicine provides interventions offering relief from pain and suffering caused by chronic conditions that are not amenable to cure. The Pathways Model, developed by McGrady and Moss (2013, 2018) is a specific model for combining patient-directed behavior change, skills acquisition, and the use of community resources, with professionally administered treatment, to reduce suffering, manage illness, and optimize *mind body spirit* wellness.

This presentation will introduce the Pathways Model and emphasize teaching self-care and self-regulation skills ranging

from mindfulness, to guided imagery, to self-hypnosis, to heart rate variability training. The presenter will provide case narratives to show the clinical benefit of regular use of self-care strategies for patients with cancer, systemic lupus erythematosus, and other chronic conditions.

Speaker Biography

Donald Moss is a Dean of the College of Integrative Medicine and Health Sciences at Saybrook University. He is a president of the Society of Clinical and Experimental Hypnosis (SCEH) and has been president of Division 30 (hypnosis) of the American Psychological Association and the Association for Applied Psychophysiology and Biofeedback (AAPB). He is a fellow of APA, SCEH and AAPB, he is a current delegate to both APA's Council of Representatives and the Council of Delegates for the International Society for Hypnosis. He is a member of the board of BCIA and serves as the ethics chair and international certification chair for BCIA.

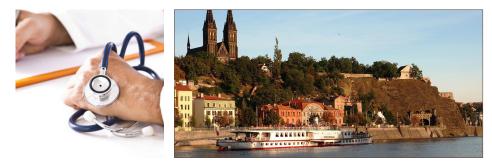
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Young children with paralytic syndromes: Maternal interview

Olena Riga and Natalia Orlova

Kharkiv National Medical University, Ukraine

Introduction: Chronic childhood pain with paralytic syndromes affects various aspects of the child and family's life, such as sleep, emotional state, relationships, development, and functional status.

Goal: Assessment of subjective vision of parents of young children with paralytic syndromes for chronic pain and their emotional status.

Materials and methods: An original questionnaire for mothers was created that included domains: child mobility, chronic pain, emotional state of the child, the child's response to rehabilitation, emotional state of mothers (neglect, anxiety, sleep, and support). 29 mothers of children aged 1 to 4 with paralytic syndromes (GMF II-V) were interviewed.

Results: Only 1 (3%) mother believed her child had no motor problem. 20 (69%) mothers complained of moderate and severe chronic pain in children. 19 (66%) respondents noted the neglect of children, and 4 (13.7%) - permanent cry or

scream. Regular rehabilitation procedures have reduced pain and improved emotional state in 8 out of 20 (40%) children. Trouble was noted by 21 (72%) mothers, poor sleep - 22 (76%), concern that children are not able to lead normal life - 21 (72%), and 12 (41%) sought empathy or understanding from anybody.

Conclusions: Physical rehabilitation of young children with paralytic syndromes improves motor activity, and in some reduces chronic pain and improves emotional state. The authors speculate improving the emotional state of the child should be ensured by improving the emotional state of mothers with the help of psychological support.

Speaker Biography

Olena Riga and Natalia Orlova are the professors in the department of pediatrics and neonatalogy in the Kharkiv National Medical University at Ukraine.

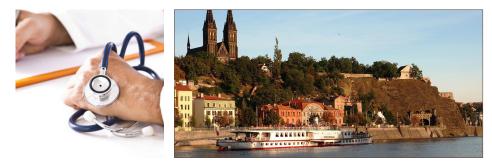
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Accepted Abstracts

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Pain and suffering: Same or not?

Syed Qamar Abbas St Clare Hospice, UK

Palliative care is defined as an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (WHO 2002)

This entails that clinical staff managing a patient should be able to identify and manage their physical symptoms as well as non-physical issues. There is a great need to understand train Palliative care staff in identifying and supporting both components. Cecily Saunders had defined 'Total pain' as suffering that encompasses all of a person's physical, psychological, social, spiritual, and practical struggles.

Suffering occurs when an impending destruction of the person is perceived; it continues until the threat of disintegration has passed or until the integrity of the person can be restored in some other manner.' To appreciate the suffering of others requires a full understanding of the personal narrative of the individual(Cassell 1991). Whereas it is important to manage physical pain, limited prognosis and physical symptoms together give rise to suffering, loss of meaning, spiritual questions and family helplessness. Medical management of death can often conceal the realisation of suffering. Patients do not tend to talk about it as they encounter more clinical questions than meaningful supportive discussions. Suffering can also stem from overzealous medical treatment and avoided conversations.

Clinicians often withdraw from those who suffer because of being unsure about further course of action, personal anxieties, fear of facing their own mortality and lack of own coping mechanisms. In an economic model, it can have impact on long term well-being as it leads to unanswered questions, unnecessary hospitalisations, difficult pre and post bereavement situation for families and unresolved questions for caring clinical team.

Conclusion: Suffering is a multidimensional experience related to physical, financial, social, psychological, emotional, spiritual, and existential anxieties. While training clinical staff in physical management of Palliative care patients, it is imperative that they are educated in recognising, researching and treating suffering of patients and their families (Breitbart 2007).

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Implementing research into practice to support carer needs of patients with life limiting conditions

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The CSNAT (Carer Support Needs Intervention Tool) approach is a person-centred process of carer assessment and support in palliative and end of life care. The research behind this tool has been conducted by Prof Gunn Grande and Gail Ewing. According to Carers UK 1 in 8 adults are carers in the UK (6.5 million) set to rise to 9 million by 2037. At the end of 2017 the Supportive and Palliative Care Team (SPCT) was approached by Gunn Grande from the University of Manchester, the aim of the research was to look at the implementation process of the CSNAT into practice as part of the discharge process in collaboration with the community Macmillan Team. The SPCT saw this as a great opportunity to implement evidenced based practice as part of a research study. The study was supported by the Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Greater Manchester. The study used a case study approach based on the MRC complex interventions framework with the utilisation of focus groups to interview the participants. The findings of this study are still under analysis and interpretation by the University of Manchester. Implementation of the CSNAT approach into practice by the SPCT provides a holistic carer led assessment and action plan of carers needs. The research which provides the evidence base and validation of the approach is informed by carers and practitioners. Early data suggests using the intervention much earlier on in the journey, providing an appropriate environment will facilitate the approach, allowing the community team to start the intervention in the community will provide us with a greater understanding of the impact of the CSNAT intervention upon carer outcomes.

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Impact of ambiguous and restrictive regulations on opioid-prescribing practice in Georgia

Pati Dzotsenidze

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While there is a wide dispute regarding long term opioid use for different health conditions worldwide, chronic pain management with opioids remains a challenge even in incurable patients in many countries, including Georgia. One of the most prominent causes of undertreating pain is overly restrictive legislation, which is regulating use of opioids for pain management. Besides the regulations, creating a variety of barriers, there are some contradictory elements within the older regulations and normative orders adopted later in Georgia, that confound the regulatory parameters and can strengthen physicians' unwillingness to prescribe such medications.

To identify barriers to pain management in Georgia we conducted a survey among 550 primary health care physicians (Family Doctors) that are responsible on opioid prescription. Overall, 289 questionnaires were analyzed. To highlight all possible consequences of the irrationally strict legislation, we studied influence of restrictions on physicians' medical practice, administrative issues, physicians' understanding of legislative aspects governing opioid use, and their impact on opioid-prescribing practice.

We found that 38% of the physicians avoid prescribing opioids at all and only one-third of them make an independent decision to treat the patients with opioids. About one-third of the physicians know the updated liberalized legislation and even fewer follow it. The physicians and administrators or managers of their health care facilities prefer to follow the old regulatory rules. Those who apply more liberal legislation and have better medical practice are investigated three to five times more by legal authorities for prescribing morphine to incurable patients than those who do not. Those physicians who know anyone that has been investigated because of opioid prescribing practice, are more concerned that they can be also investigated. Physicians who are concerned that they might be investigated are less inclined to prescribe opioids or use liberalized regulations. Hence, ambiguous legislation negatively influences opioid-prescribing practice.

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"Schubert dressing": Musical counter-stimulation to accompany painful interventions

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Context: Benefits of music therapy to patients hospitalised in palliative phase have previously been reported (OPPERT, 2012, 2014, 2016).

Objective: To observe potential sensory counter-stimulation effects in patients in a palliative care unit exposed to music during painful care interventions: bathing, dressings, intravenous or intra-abdominal catheter insertion. Study concerned: patients 80% oncological, 10% neurological; 20% dementia, 5% psychotic; 230 hospitalisations per year; 10 beds; average stay 12 days.

Method: Open, monocentric, prospective study by a music therapist/cellist intervening at patient's bedside. Analysis of 200 "Schubert dressings" over 2 years in collaboration with Unit's health personnel. All patients consented consecutively to receiving music therapy or not to accompany painful intervention. Following data compiled on a specific observation form: age, pathology, cognitive status, art tastes, intervention type, pre-medication, session length. Following data compiled before, during and after intervention: pulse rate/BP, respiratory rate, thoracic expansion, pain status (VRS,

BRS), communication and anxiety (expressed directly and hetero-assessed indirectly), patients' and carers' sentiments.

Results: Earliest results (intermediary results of 50 dressings based on forms reporting comparatively with and without musical counter-stimulation) reveal:

- 10-50 % pain reduction with "Schubert dressing", showing musical stimuli can relieve pain sensation
- muscle relaxation
- reduction in anxiety
- beneficial effect on carers

Conclusion: Despite methodological difficulties, discussed and analysed, associated with assessment – difficulty applying scales approved for long term assessment used over a short period, and issues of subjectivity – due to carers' responses to music therapy session, "Schubert dressing" sessions had significant positive effects on feelings of pain and anxiety experienced by patients during painful interventions.

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Traditional and complementary medical practices in geriatric palliative care

Sibel Doğan

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Aging population has almost become a global issue because aging population causes crucial problems in the world. Life expectancy at birth rises all over the world; which has resulted in increasing rate of the elderly population. Elderly individuals are the primary consumers of health and social care services and therefore, provision of a good service is of critical importance for their quality of life. That is why recent studies have focused on palliative care in geriatric population. Today, most of the palliative care patients are composed of geriatric patients. Holistic and integrative palliative care - assessing the elderly individuals' physical, psychological, spiritual, socio-cultural and environmental comfort needs- targets at their unmet needs through comfort building practices. To provide and to maintain comfort in palliative care, it is important to control pain and other disturbing symptoms as well as psychological, social and spiritual problems. Hence, evidence based traditional and complementary medical practices can be helpful.

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We need to talk about Trissomy 18

Maria Augusta B Cicaroni Gibelli

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Trissomy 18 (T18) is the third most common chromosomal disorder and a life-limiting condition. Recently, major surgical interventions have been related to longer survival. When should we consider curative and palliative care?

Aim: To describe the treatment performed for patients with Trissomy 18 in a Tertiary Neonatal Intensive Care Unit (NICU).

Methods: Retrospective cohort of newborns with confirmed diagnosis of Trissomy 18 by karyotype.

Results: During a 19 months period, 2074 newborns were admitted; 13 had Trissomy 18 (6.3:1000 live births). The average time of hospitalization was 44 days. There were 9 (69.2%) deaths; 4 (30.8%) infants were discharged to their homes. The average age of death was 35 days of life. All the patients of the sample died before 1 year old. Non-invasive ventilation was used in 6 (46.2%) for an average time of 15,2d. Invasive ventilation was used in 4 patients (30.8%) for an average time of 12.5 d Cardiac surgery was performed

in 2(15.4%) patients;1 died after the surgery, the other was discharged, but died with 7 months of age. In 2 (15.4%) patients, the prostaglandin use was discontinued after discussing the options with the families. Abdominal surgeries were performed in 3(22.6%) patients with esophageal atresia (2) or omphalocele (1). Gastrostomy was performed in 8(76%) patients. The goals of care were discussed with the multidisciplinary team and the parents were encouraged to participate in all decisions.

Conclusions: In most patients, the treatment included mechanical ventilation and surgical procedures. A palliative care protocol to approach Trissomy 18 is necessary. All possible disclosures and treatments should be discussed with the parents considering the high morbidity and mortality of each intervention made.

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